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ABSTRACT

This report is based on a 1988 site visit to the Northeast Educational Services Cooperative (NESC) in South Dakota. The visit's purpose was to provide consultation and recommendations regarding residential options to support children with severe disabilities who typically have been placed in out-of-district residential placements. Background information on the NESC, the South Dakota Department of Education and Cultural Affairs, and other relevant agencies is provided. National trends in supporting children with severe disabilities in families (birth families or adoptive or foster families) are cited. Essential program components for supporting children with severe disabilities are discussed, including family supports and permanency planning. The status of best practices in South Dakota is reviewed. Strengths of this rural area are also noted, such as strong family ties, local community values, broad community commitment, potential leadership, and some support services. Problems and concerns identified include the issue of economic priorities versus children's priorities, facility size, lack of information on funding, lack of information on best practices, lack of family involvement in planning, and role confusion in interagency collaboration. Recommendations are offered to the NESC and to the Section of Special Education of the Department of Education and Cultural Affairs. (Includes a list of 13 additional resources.) (JDD)

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Center on Human Policy

RESIDENTIAL SUPPORTS FOR CHILDREN WITH SEVERE DISABILITIES IN NORTHEAST SOUTH DAKOTA

EC 300645

BEST COPY AVAILABLE

Residential Supports for Children with Severe Disabilities in Northeast South Dakota

January 1989

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Northeast Educational Services Cooperative
and
South Dakota Department of Special Education

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INTRODUCTION

THE SITE VISIT

This report is based on a site visit conducted on August 8-9, 1988 to the Northeast Educational Services Cooperative, one of a growing number of educational cooperatives in South Dakota. The consultation was arranged and primarily funded by the South Dakota Department of Education and Cultural Affairs, Section on Special Education, as part of their assistance role to the cooperative. One consultant was identified through the technical assistance network of the National Association of the Severely Handicapped (TASH) and another selected based on his extensive experience in supporting people with severe disabilities in rural areas.

The primary purpose of this visit was to provide consultation and recommendations to the Northeast Educational Services Cooperative regarding residential options to support children with severe disabilities who typically have been placed in out-of-district residential placements, such as Redfield, one of the two state institutions for people with mental retardation, and the Crippled Children's Hospital and School, a private, non-profit special school and hospital.

As requested by the Department of Education and Cultural Affairs, this report addresses these major questions:

1) What are some viable options/recommendations for this rural area to provide services to these multi-handicapped children?

2) What are some initial steps/considerations in establishing these services?

3) Are there established programs within the surrounding region that could be used as a model?

The site visit included discussions with representatives from six communities that expressed an interest in supporting children with severe disabilities currently in out-of-district residential placements. The discussions took place with each of the six school superintendents in the communities of Volga, Estelline, Clear Lake, Castlewood, South Shore, and Clark and with community and school representatives (e.g., the mayor, school principal, members of economic development committees) in four of these districts. A program specialist with the Department of Education and Cultural Affairs and the assistant director of the Northeast Educational Services Cooperative participated in all discussions.

In addition, the consultants visited with three children from the cooperative area who currently live at Redfield, the director of the Northeast Educational Services Cooperative and a family with a child with a severe disability who is living at home. Written information, including Status Report: Special Education in South Dakota: 1987-88, and six proposals prepared by the communities for the development of a fifteen (15) person intermediate care facility, provided background information. This report also draws upon the extensive experience of the Research and Training Center on Community Integration in studying innovative practices nationally in supporting children with the most severe disabilities in community living.

The draft report was presented via teleconferencing to the Board of the Northeast Educational Services Cooperative. This final

version reflects additional discussion of key issues with the director and assistant director of the Northeast Educational Services Cooperative and with the program specialist and director of the Department of Education and Cultural Affairs, and written responses collected by the cooperative.

BACKGROUND INFORMATION

DEPARTMENT OF EDUCATION AND CULTURAL AFFAIRS

In South Dakota, the Department of Education and Cultural Affairs has the primary responsibility for serving children with developmental disabilities. The Section of Special Education (SSE) of the Department of Education and Cultural Affairs (DECA) has the responsibility to "(1) supervise and coordinate all special education programs operated by public, state and non-public school agencies; (2) develop and provide information about state special education programs; (3) enforce and interpret special education programs; (4) supervise federally funded special education programs; and (5) participate in coordination activities between other state agencies."

The provision of special education is mandated in South Dakota's Constitution and predates the enactment of the federal Education for All Handicapped Children Act of 1975 (PL 94-142). All children, birth through two years of age, who are deemed in need of "prolonged assistance" are entitled to special education services. For all other children, special education services are available from the ages of three through twenty-one.

The school districts have legal responsibility for providing appropriate services, and are reimbursed 50% of the allowable costs expended by the local district for the operation of their special education programs. If a child is placed at a state institution (i.e., Custer or Redfield State Hospitals) or at a state school for the blind or deaf, the state covers 100% of the cost of the 24-hour residential placement.

OTHER RELEVANT AGENCIES

Several other state offices have important roles related to the children's services issues discussed in this report. The following information is excerpted from the Developmental Disabilities State Plan and from a report by the National Association of State Mental Retardation Program Directors on South Dakota.

1) The Office of Medical Services of the Department of Social Services (DSS) is responsible for the administration of the state Medicaid plan, including services provided in intermediate care facilities (ICFs) and through the Title XIX home and community-based Medicaid services waiver.

2) DSS's Office of Child Protection Services, among other responsibilities, oversees the provision of foster care for children in need of protection, administers the state's adoption subsidy program and in some ways acts as an external casemanager for the provision of services for children with developmental disabilities.

3) The Department of Health regulates specialized residential services for people with developmental disabilities in the community and institutions. It also plays a significant role in regard to

services such as child find.

4) Board of Charities and Corrections supervises the two state institutions at Redfield and Custer, among others.

5) Office of Developmental Disabilities and Mental Health (ODDMH) is the lead agency for community services for adults with developmental disabilities, but has a more limited role regarding children. This office funds the nineteen private, nonprofit adjustment training centers which provide services for people with developmental disabilities in their catchment area. The adjustment and training centers may also accept clients and funding from other agencies, including the local school districts.

NORTHEAST EDUCATIONAL SERVICES COOPERATIVE

As of December 1, 1987, the Northeast Educational Services Cooperative was one of thirteen educational cooperatives operating in South Dakota. Based on 1979 legislation, several school districts can pool their resources to provide important services to children through the establishment of a cooperative. Cooperatives provide a wide range of services either directly or through the purchase of services from other agencies.

The Northeast Educational Services Cooperative was approved in 1981 and serves an area of 3,561 square miles. As of December, 1987, the cooperative represented sixteen (16) school districts with a total enrollment of 5,183 students. It provided psychological and administrative services, gifted, early childhood and special education programs, and speech/language therapy directly and occupational and physical therapy through the purchase of the

service mechanism. The services in this cooperative are partially supported through membership fees from the school districts.

Currently, in contrast to at least one other cooperative, the Northeast Educational Services Cooperative and its school districts do not directly or indirectly operate any in-district residential services, such as foster care, for children.

THE PROPOSED RESIDENTIAL PROJECT

BACKGROUND ON THE PROJECT

The Northeast Educational Services Cooperative recognized a need for residential services for children early in its inception. In 1986, a physician who had a daughter with a disability initiated an effort to convert a wing of a nursing home in Lake Preston for use by people with mental retardation. His main concern was to keep his daughter near home and to enable her to be integrated into the local public school. Because of regulatory and other bureaucratic issues, the project was never completed.

As an alternative, the cooperative decided to examine the feasibility of building a "15-bed" intermediate care facility (ICF-MR) that could be located in one of the local communities. The cooperative developed a "24-hour program site survey" that was distributed to local communities within the cooperative area. In June 1988, six communities formally returned the surveys and requested consideration as a possible site for the facility. The communities applying for consideration were Volga, Estelline, Clear

Lake, Castlewood, South Shore, and Clark.

While the decision regarding the type of residential services or supports is reportedly that of the cooperative, without the support of the state Department of Education and Cultural Affairs, it will be extremely difficult for the cooperative to develop an intermediate care facility. The Section of Special Education recognizes that the proposed project, particularly the size of the facility, is inconsistent with best practices nationally. The cooperative's director, Doug Brusseau, however, maintains the development of such an intermediate care facility is essential.

NATIONAL TRENDS IN SUPPORTING CHILDREN WITH SEVERE DISABILITIES

A primary purpose of the consultation was to share with the Northeast Educational Services Cooperative and the Department of Education and Cultural Affairs national trends and innovative practices in supporting children with severe disabilities in the community. In particular, the state office and selected members of the cooperative expressed interest in information on best practices in rural areas.

As described in on-site meetings in South Dakota, current best practice is to support children with severe disabilities in families - birth families or when necessary, adoptive or foster families. Children with the most severe disabilities, including children with complex medical needs, behavioral issues, and multiple disabilities, are today being supported to live with families. (Taylor, S.J., Racino, J., Knoll, J. and Lutfiyya, Z., 1987). This practice occurs

in both rural and urban areas in various parts of the country.

There are several critical aspects that are important to insure that children can be supported to live with their families in quality ways. Two of these, family supports and permanency planning, are discussed in more detail below. The Center on Human Policy is regularly involved in the study of best practices in supporting children in the community. We can provide additional information in this area including qualitative research reports, site visit reports, journal articles, and lists of resource and contact people.

FAMILY SUPPORTS

Across the country, there is a growing recognition of the importance of providing families with the supports they need to keep their child with a disability at home (Bates, 1985; Agosta and Bradley, 1985). Unlike past years when families had only two options - keep their child at home with no or little supports or place their child out-of-home often in an institution - families are now receiving increased resources in order to maintain the integrity of the family unit and support their child at home.

Best practices in family supports include an emphasis on a family-centered approach, the provision of individualized and flexible supports, the coordination of those supports through responsive casemanagement, the advocacy and empowerment of families and building on natural community supports. Types of supports available to families could include, but are not limited to, home modifications, adaptive equipment, respite, in-home assistance,

transportation, recreational opportunities, parent training, counseling, in-home training and support by specialists (e.g. occupational therapist), and financial subsidies.

In general, rural areas are in a better position to implement the current best practices in family supports than many urban settings. Rural areas, such as South Dakota, often have a strong emphasis on "taking care of our own" and a strong history of looking for unique solutions to supporting a specific family or child. Information on family support programs, including rural areas in Wisconsin and Montana are attached.

PERMANENCY PLANNING

There are situations and times where even with support services, it may be necessary for a child to live away from the birth family. A permanency planning approach supports the family's ongoing relationship with the child and aims toward family reunification. If a child must live outside the birth family, the family is offered foster care as a temporary placement, with the goal of returning the child to the family. When this is not possible, other options such as adoption (including "open adoption" where the birth families stay involved), shared care, and permanent foster care are pursued (Taylor, et al, 1987). Of course, family supports are also available to the foster and adoptive families. The implementation of permanency planning in Macomb-Oakland, Michigan, an area with a general population of two million, has resulted in all but six of the children with developmental disabilities now living with families.

A responsive foster care system is one component of a permanency planning approach. There are many excellent examples of children with severe disabilities being supported in foster families, including in many rural areas of the country. As of August, 1988, Region V in Nebraska, for example, had twenty-seven children living with foster families. Foster families receive training, and other supports such as in and out-of-home respite on both a planned and emergency basis, in-home supports from 8 - 80 hours per week depending on the needs of the specific family, transportation assistance and case management. In addition, in "extended family homes," foster families may receive a stipend of from $250 - 500 per month. Excellent foster homes for children with severe disabilities, including those with challenging behaviors, can also be found in other places such as Louisville, Kentucky.

STATUS IN SOUTH DAKOTA OF BEST PRACTICES

The following information is included in this report to provide a state context for the analysis and recommendations that follow.

First, in the area of family supports, we would like to share the following excerpts from a July 1988 report by the National Association of State Mental Retardation Program Directors:

> Our review of current programs in South Dakota failed to turn up any program that might be viewed as a comprehensive, integrated strategy for extending the full range of family support services to a broad-based population.

It is also clear that South Dakotans, by and large, have not given a good deal of thought to how a family support program might be structured and organized.

The information stated above is consistent with our observations during this consultation. The people we met have insufficient information on the concept of a comprehensive, family-determined program of family support.

Second, the state of South Dakota has not formally instituted a permanency planning approach for children with developmental disabilities who are not covered by federal law P.L. 96-272 (Taylor and Lakin, 1988). This is not surprising since family support, a key aspect of any permanency planning approach for children, still has not been addressed. There is no official state policy to support children belonging in families.

Third, in the area of foster care, it is our understanding from one of the state program specialists that there are good examples of specialized foster care in the state, including foster families supported through the Black Hills Special Services Cooperative. The homes in Black Hills are reportedly operated by a private, non-profit provider through an agreement with this cooperative and are valued because of their long-term stability.

It is our understanding that the Department of Education and Cultural Affairs is in the process of a statewide best practices search for supports to children and their families.

BUILDING ON STRENGTHS

This section focuses on the Northeast Educational Services Cooperative and draws heavily on discussions and observations during our two day visit.

STRONG FAMILY TIES

Compared to situations we have seen in other states, we were impressed with the apparent strength of family ties with the children who are placed out-of-home, either in the institution or in other out-of-district placements. Several indicators of these ties include frequent visits by family members and the many positive descriptions of the relationships between families and their children shared with us by staff in the institution and community members.

We were greatly concerned, however, that in some situations the stated reason for out-of-home placement could have been addressed by supports to the family, if such supports were available in this area of South Dakota. For example, in a few instances, the only stated reason by professionals and community members for the necessity of out-of-home placement was the fact that both parents worked and could not directly provide or pay another person for child care. By providing access to child care or a subsidy, it seems likely that out-of-home placement could have been averted.

The strong family ties are a critical strength and indicate a sound base for building the family support program necessary for children to be supported in living at home with their family.

LOCAL COMMUNITY VALUES

We were also impressed with the clear concern by a number of the community groups to do what was best for the children. Economic benefits did play a major role in the applications, but in at least two communities the needs of the children clearly were of primary concern.

In addition, a number of school leaders recognized that integrating the children with severe disabilities was also important for the other young children in the school. As one superintendent said, "having the handicapped children here will be a growing experience for the other young people, too." This theme was repeated by a principal in another district who said, "this is equally important for these (typical) children."

Many of the community representatives described their communities as caring and compassionate. They described the resources of the local community and how the children with disabilities would be able to participate in community life. As one representative stated, "we want people to live and be part of what goes on here in (name of the community)."

One of the initial intents of the development of this project - to bring the children nearer to home - came up repeatedly in the visit. Bringing the children nearer to home and to the family is an important value and a clear strength to build on in developing the supports that families need to care for their child.

BROAD COMMUNITY COMMITMENT

We were impressed by the efforts in at least four of the

communities to develop a broad base of support for the project. Through the development of the proposals, the districts engendered a tremendous amount of community awareness and support, ranging from petitions signed by community members to commitment by churches and key community leaders.

While the recommendations made in this report vary greatly with the expectations of the community groups, the words of one community leader are critical: "We are willing to adjust to what will work out best in the long run in the community." What will work out best for the community certainly needs to include what is best for the children, their families and neighbors. While partially motivated by expected economic returns, the local energy developed through this project can also serve as a basis for the community action necessary to implement the recommendations made in this report.

POTENTIAL LEADERSHIP

We identified a number of key people who could play a significant role in implementing the recommendations contained in this report. Provided with information and support, these individuals seem willing and able to be on the forefront of changes in more fully integrating the children with severe disabilities into schools and communities in northeast South Dakota. As one school leader stated:

> The concept sounds great. South Dakota has to start putting money into it. I know the program would work here.

With information, resource support and leadership from the cooperative and/or the state office, these individuals can play significant roles in developing a system to support children and their families in the northeastern section of South Dakota.

SUPPORT SERVICES

We were surprised to learn that most communities believed that the necessary medical-related support resources already existed in reasonable proximity to their communities. The cooperative itself offers a number of support services in areas such as occupational, speech and physical therapy as well as psychological services. In addition, medical services do appear to be available in several communities and relatively easily accessible in the region.

PROBLEMS AND CONCERNS

This section looks at problems and concerns identified through an examination of this specific cooperative region.

ECONOMIC PRIORITIES VS CHILDREN'S PRIORITIES

The area served by the Northeast Educational Services Cooperative has many small towns whose economic survival depends on their ability to attract new industry. The development of a "15-bed" facility could result in new jobs necessary for the towns' survival. This economic issue has at many times overshadowed a reasonable discussion on what is best for the children and their families.

The original facility-based proposal required the identification of one community as a residential site within the cooperative region for children with severe disabilities. By supporting children in birth, adoptive or foster families, each local community can benefit somewhat economically since children would typically be returned to their home communities.

In addition, one of the advantages of an individualized approach to supporting families, is the focus on one family at a time. Thus, community (including school) capacities can be developed throughout northeastern South Dakota to better integrate the children back into their home communities and to maintain children in families who are currently living at home.

FACILITY SIZE

The proposed size of fifteen (15) people for the facility is inappropriate on a number of grounds:

1) Based on the information we have, even assuming a group home was appropriate for the children (which we believe it is not), there are only six children identified for the home. A home for fifteen people will encourage further out-of-home placements resulting in increased costs.

2) In a number of progressive states, the size of homes for adults is being reduced to four or fewer people, especially for people with the most severe disabilities. It is unreasonable to actually construct a facility for fifteen people at a time when the general direction is toward decreased size.

3) A home for fifteen people is too large even in a large

metropolitan area; it is totally incongruous with a small town, rural atmosphere.

4) None of the towns we visited appears to have the capacity to develop and manage an intermediate care facility of this size. All representatives had limited knowledge about the actual scope of the proposed project. Even if constructed, the home could easily be in jeopardy of losing federal funds for lack of compliance.

5) The project will be a costly one and will involve the use of state as well as federal funds. The state share alone could be better used for family supports and responsive foster care.

6) The cooperative itself has limited experience in areas outside the direct educational sphere, is generally unfamiliar with the development and operation of intermediate care facilities, and has inadequate information at this time to pursue such a project.

Above all, a facility for fifteen people is not in the best interests of the children. No group living facility can provide the long term relationships with adults and the permanency of a family necessary for the children. Also, this project should not be pursued because it is fundamentally unsound on the grounds of capacity, need and fiscal responsibility.

LACK OF INFORMATION ON FUNDING

Discussions with the cooperative and the applying school districts and communities indicate a tremendous lack of information on the local level regarding the funding of residential services and supports for children. The basic information gathering process that should occur before such a project was proposed apparently still has

not taken place.

As one example, the cooperative is unaware of other possible funding sources, including federal financing through the Title XIX home and community-based Medicaid waiver. The waiver has been used in other states to provide in-home family supports and to support people in smaller, typical homes. It is of great concern to us that none of the people we met during our visit had information regarding the use of the waiver in South Dakota for children.

This is not to imply that we recommend the use of Medicaid funds (even the waiver) for family supports. Typically, areas such as family supports are better funded through state dollars due to the heavy emphasis of the Medicaid funding stream on medical issues and the relative inflexibility of this funding source. We were not able to discuss this issue during the visit because the people we met did not have information on initiatives and/or the responsibility of other state offices such as the Office of Developmental Disabilities and Mental Health (ODDMH) regarding areas such as family supports.

In addition, several of the letters we received as comments to the draft of this report indicate a lack of information about proposed Medicaid reform legislation and its implications for South Dakota. Information on even more immediate issues affecting the Title XIX Medicaid waiver program (e.g., new federal ICF-MR standards) are also not known.

It is important to note that the issue of funding is a critical concern expressed by all the superintendents. Comments such as "our special education budget already exceeds the budget of our high school" illustrate that this concern by the superintendents must be

adequately addressed. At the time of our visit, the cooperative and the school districts did not have information regarding the funding that is (or even might be) available to support children in birth, adoptive or foster families.

LACK OF INFORMATION ON BEST PRACTICES

In our meetings, it was evident that a number of people we met could benefit from an opportunity to visit rural areas where children with severe disabilities are being supported in birth, adoptive or foster families. Region V, Nebraska is willing to conduct a study tour, if requested, to enable a group of people from the northeastern area of South Dakota to visit families in Nebraska. Other examples of family supports offered under the Medicaid waiver can be found in nearby Minnesota.

Although we did not formally assess the children we met at Redfield, it is our impression that the young children would be relatively easily supported in family situations. Compared to people we have seen in other states, the children we met do not seem to have as serious medical or behavioral needs. We believe there is a need for people in the Northeast Educational Services Cooperative to have an opportunity to learn about and visit places that are supporting children in families and to broaden their vision of what is possible for children with severe disabilities.

LACK OF FAMILY INVOLVEMENT IN PLANNING

In addition to the involvement of parents in planning services for their child, it is critical that parents of people with

disabilities be actively involved in broader planning efforts. It was striking that the cooperative seemed to have no formal mechanism for obtaining input from parents (e.g., advisory board) and that the proposals for the intermediate care facility development did not indicate strong parental involvement in the project.

ROLE CONFUSION AND INTERAGENCY COLLABORATION

Many of the issues regarding residential services raised in this report revolve around the unclarity of roles between different state offices in areas such as family supports and on the way in which this role unclarity affects the relationships of their respective representatives at the local level.

One of the key planning decisions that has not been adequately addressed is whether or not the cooperative should actually be the lead organization in the development of family support services, foster care and other residential supports for children. While the Section on Special Education has responsibility for children with developmental disabilities, decisions regarding their role in emerging areas such as family supports is still unclear. This finding is echoed in the previously referenced report by the National Association of State Mental Retardation Program Directors that states: "If South Dakota is to implement a family support program, the most difficult question the state will have to answer is which state agency will be assigned responsibility for administering the program."

Before a project of any significant size is pursued the cooperative needs clearer information and direction from SES. The

following are examples of some of the information required by the cooperative for reasonable planning and development to occur:

1. What is the responsibility of the state Office of Developmental Disabilities and Mental Health regarding areas such as family supports? Although some family support services can be provided through designation in the IEPs as educationally related services, in most states, the office of developmental disabilities has initiated family support programs to enable children with disabilities to remain home with their families.

2. What is the responsibility of the state Office of Developmental Disabilities and Mental Health and/or the Office of Medical Services regarding the use of the Title XIX Medicaid waiver? Most states, including South Dakota, have a home and community-based Medicaid waiver that can allow for the development of more integrated community supports for people who are designated as requiring an "ICF-MR level of care." Our understanding is that the South Dakota waiver has been renewed. Are the children in Redfield and the Crippled Children's Hospital eligible for services through South Dakota's waiver? If not, could they be? What services are available to them under the waiver? What is the process of accessing this funding?

3. What is the responsibility of the Section on Special Education to the cooperative regarding the development of children's residential services in the state? In starting a major endeavor such as the development of supports for children with severe disabilities, it is critical that the cooperative obtain information on the types of assistance available from the state level, in terms

of technical support, start up and ongoing funding.

In addition, it is the responsibility of the Section for Special Education to obtain and disseminate information to the cooperatives about the roles of other state agencies in areas such as the home and community-based Medicaid waiver. If cooperative agreements between state agencies on these issues do not already exist, they must be developed.

4. <u>What is the role of the cooperative and the school districts regarding the development of children's residential services in the state</u>? We are concerned about the capacity of the cooperative and/or school districts to both integrate the children into the school systems and also be a primary facilitator of the residential services. It is critical to note that the districts we visited have limited experience in integrating the children we met into the public schools. As children return from institutions to be educated in their home communities, the cooperative will need to assist these districts in developing the capacity to integrate these children into the schools.

Our limited experience during this visit leads us to question whether it is appropriate for the cooperative to be the lead agency for residential services for children. This issue should be re-examined at the state level, especially in light of the systems concerns noted in the report by the National Association of State Mental Retardation Program Directors regarding the emerging potentially duplicative, parallel service delivery systems operated by the cooperatives and the adjustment and training centers.

These are a sample of some of the critical role responsibilities

that need to be addressed. Similar interagency issues need to be addressed with other state agencies, including DSS's Office of Child Protection regarding foster care.

SUPPORTS AND SERVICES AS OPPOSED TO FACILITIES

This section is included to highlight some of the differences between planning and services development for a "residential facility" as opposed to supports for children and their families.

THE INDIVIDUAL AND FAMILY PLANNING PROCESS

The original process started with the planned development of a facility with the intent to "fit the children into the program" and with no involvement of the families in the process. The process we recommend should instead start with the individual child and their family, not with the plan for a facility.

The first step is a community assessment of each individual child that includes the identification of services needed by the child and their family. For a good description of this type of community assessment (as opposed to the standard developmental or deficit-based assessment), see Brost and Johnson's Getting to Know You: One Approach to Service Assessment and Planning for Individuals with Disabilities. For children, the assessment should be family-centered and focused on the needs of the family unit as opposed to just the child with a disability. We can provide a sample family plan from Wisconsin that may be useful. In addition, the parents should be involved from the beginning in the process of

identifying and determining the services and supports that are needed. These supports also should be changeable over time as the needs of the family change. This applies to birth, adoptive and foster families.

SERVICES AND SUPPORTS

As described in the section on national trends, the question no longer is can children with severe disabilities be supported in birth, adoptive or foster families. We have examples, rural and urban, of children with the most complex needs being supported to live at home. The major question today is what do we need to do in order to provide the needed quality supports? This may require legislative, administrative and/or regulatory changes at the local, regional or state levels.

As a suggested guiding statement of principles, we have attached a Statement in Support of Families and their Children (Center on Human Policy, 1986) developed at a policy institute of national leaders on supporting children with severe disabilities in the community. This statement has been endorsed in modified form by national organizations such as the National Association of Retarded Citizens (ARC-US) as well as statewide organizations such as the Louisiana Developmental Disabilities Council and the Connecticut Department of Mental Retardation. This statement can serve as a common framework for future services development for children.

In the northeastern area of South Dakota, family supports are available on a very limited basis (if at all to some families) and no specialized foster care options with the necessary supports

exist. Several people we met mentioned that some children would still need placement in a facility even if these supports were made available. However, it is important to note that none of these individuals had ever seen a quality family support system; all are unaware of permanency planning approaches; and each equated foster care with the current system of generic foster care in South Dakota that they considered inadequately monitored and supported. Thus, it is critically important for people in this region to have exposure to current best practices in supporting children with severe disabilities in families.

As described under the section on permanency planning, foster care is one part of the network of services and supports that needs to be developed in this region. Given the small number of children involved, only a few foster families need to be recruited. If adequate supports are available, quality foster families should be relatively easy to find. We have additional information on the recruitment of foster families; Region V, Nebraska has also offered to act as an information/training resource in the area of recruitment.

The development of a system of family supports and quality foster care will require a responsive system of casemanagement, a system currently not in place. The representative from SSE, however, noted the state recognized the importance of casemanagement in insuring quality and could work with the cooperative to obtain this essential resource.

RECOMMENDATIONS FOR THE COOPERATIVE

The following is a summary of initial recommended steps for the cooperative.

1. The cooperative should not develop an intermediate care facility, especially a "15-bed" facility for the children.

The plan by the cooperative to develop the intermediate care facility is inappropriate for the children and inconsistent with current best practices for supporting children and their families. In addition, the proposal for the intermediate care facility is not based on sound planning in the following areas: capacity, fiscal responsibility, needs assessment, state-local relationships, and programmatic issues.

2. The cooperative director, with support from the cooperative board, should immediately convene a local task force committed to supporting children and their families.

The cooperative director needs additional information for sound planning to occur in supporting children and their families in northeastern South Dakota. This includes information on the present and potential funding of residential supports in South Dakota, the needs of families in the cooperative area, the needs of each of the children placed out-of-home, best practices for supporting children and their families, implementation strategies, and state-local relationships.

The task force should include parents, people with disabilities, school leadership and other personnel, community leaders, key state

and local organizations (e.g., the Office of Developmental Disabilities and Mental Health, the Department of Social Services, the Special Education Section of the Department of Education, the Department of Health, the adult training centers) and others committed to supporting children in families.

3. The task force should complete the following within three months:

(a) Develop a core group of people familiar with current best practices in supporting children and their families. For example, a speaker could be invited from the Black Hills area to talk about foster care development in the western part of the state. Selected members of the task force could visit a rural area such as Region V, Nebraska to examine in more detail how supports are provided. The Center on Human Policy can provide extensive resource information in this area.

(b) Obtain input from families on the supports they need to maintain their child at home. Sample surveys and interviewing formats used in other states can assist the committee to obtain information on supports needed by families, including major gaps in the current system. This also is another opportunity to involve families in the planning process.

(c) Identify currently available resources that could be used to support children and their families. Sometimes by looking at existing resources from a new perspective, additional sources of support can be identified. In addition, efforts across agencies can also yield an increased capacity to respond to families.

(d) Propose a position statement of principles in support of

children and their families for adoption by the cooperative board and other key local groups serving children and their families. Minimally, it is essential for lead organizations involved in services for children and families to publicly state their support for maintaining the integrity of the family and their intention to seek to provide the necessary resources. The statement in support of children and their families can serve as a sample statement for discussion.

(e) Clarify local roles and relationships regarding supports for children and their families. The task force can seek clarification from the state agencies on role responsibilities. However, even without agreement on the state level, a tremendous amount can be accomplished through the coordination of planning on a local level.

(f) Clarify possible funding options in the state for supporting children and their families. The task force can review the available and planned funding for services for children and families in South Dakota. They can develop recommendations regarding priorities for future funding.

(g) Develop recommendations regarding future service development for children and their families in the northeastern region. These recommendations should be formally presented to the cooperative, relevant state agencies, and the state task force on supporting children and their families.

4. In light of the major issues with this project, the cooperative board should re-examine its planning process for services. Included in this review, should be an assessment of state-local relationships, a re-examination of the role of the cooperative

director, and a mechanism for inclusion of family input in the planning process.

5. The cooperative board should work with SSE and other agencies serving children and their families to plan for each child to return from out-of-district placements to their home community. It is our understanding that SSE has offered to work together with the cooperative regarding each individual child. It is essential that the cooperative board develop a collaborative relationship with SSE on this issue.

RECOMMENDATIONS FOR THE DEPARTMENT OF EDUCATION AND CULTURAL AFFAIRS, SECTION OF SPECIAL EDUCATION

These recommendations are made primarily to clarify for the cooperative what we see as reasonable steps on the part of the Section on Special Education of the Department of Education and Cultural Affairs.

1. Develop a state task force to address some of the state legislative and administrative issues that may be involved in the development of supports for children and their families in South Dakota.

(a) It is our understanding that such a task force is established and in the process of collecting information throughout the state. Although inclusion of the Northeast Services Cooperative on the task force is not essential, it would be useful for local groups (such as the recommended task force in this region) to know how they can give input to the state task force.

(b) The early development and promulgation of a written statement of principles and directions on supporting children and their families would clarify the formal directions of the state of South Dakota in these important areas.

(c) Information on the role of the task force and the expected timetable for task completion would also be useful information on the local level.

2. Make accessible current information on funding for services for children and their families in South Dakota. A simple fact sheet on current funding sources, amounts, responsible agency, process for accessing funding, and eligibility would be useful.

3. SSE should formally offer to assist the cooperative in planning for the return of each of the children currently in institutions to an in-district placement with a family. It is our understanding that SSE is willing to work together with the cooperative on this issue. We recommend that SSE formally extend this offer to the cooperative and that they work jointly to identify specific barriers for each child and strategies to address these barriers.

In addition to these immediate steps, on a statewide basis, there is a need for a comprehensive family support program, the development of a policy on permanency planning for children, and the clarification of children's roles among the various state departments. As mentioned in the report, the role of the cooperatives in developing and operating residential services (either directly or indirectly) also merits re-examination.

CONCLUSION

This report provides information regarding national trends in residential supports for children with severe disabilities and their families, examines selected strengths and problems in the northeastern region of South Dakota, and suggests some initial steps that can be pursued by the cooperative and by the Department of Education and Cultural Affairs to improve the quality of life of children and their families in South Dakota.

A tremendous amount of work in the area of supports to children and their families needs to be done. We hope the major difficulties associated with this project can be laid aside and that all parties can work together for the betterment of the lives of children with disabilities and their families in northeastern South Dakota.

We would like to thank each of the superintendents, community representatives, institutional staff and parents who met with us during our visit to South Dakota. Special thanks is extended to Phylis Graney from the State Department of Special Education and Bill Mueller from the Northeast Educational Services Cooperative who accompanied us on these visits.

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